Surgery for pancreatic cancer
Patient Information Booklet

Building healthier lives
UHB is a no smoking Trust

To see all of our current patient information leaflets please visit www.uhb.nhs.uk/patient-information-leaflets.htm
Introduction

This booklet contains information about the different types of surgery performed to treat pancreatic cancer.

There are also facts and figures about the success and possible complications of pancreatic surgery.

Please remember this booklet is not a substitute for asking questions of your doctor and specialist healthcare team. You are always welcome to ask questions and we would encourage you to do so.

Surgical options

You have been advised that an operation to remove the cancer from your pancreas may be possible.

There are several different operations used to treat pancreatic cancer. We know that removing the cancer via an operation is the only way in which this cancer can be cured.

The cure rate for patients, who have had their pancreatic cancer resected successfully is one in five. This means that out of five patients who have their cancer removed, one patient will be cured and this cancer will not come back. The remaining four patients will have the cancer return within about two years.

Removing the tumour completely

To find out whether this is possible for you, your surgeon will look at:

- The size of the tumour
- Where it is in the pancreas
- Whether the cancer has grown into the tissues around the pancreas
- Whether the cancer has grown into the major blood vessels in or around the pancreas
- Whether the cancer has spread to any other parts of the body
Your surgeon can find the answers to some of these questions from your pre-operative tests.

The specialist team here will have looked at the CT scan you had in your referring hospital. Your scans may show the size and position of the tumour which helps the team plan your surgery. Scans may also show up cancer spread to other parts of the body. But it may be necessary for your surgeon to try the operation without knowing exactly whether the cancer has spread to lymph nodes or invaded blood vessels.

If it is possible to remove your cancer you may be offered one of the following:

- Whipple’s operation
- Total pancreatectomy
- Distal pancreatectomy

These are highly specialised operations. The best surgical results come from specialist centres. Surgeons that work in specialist centres do more of these operations. Government guidelines state that there should be one specialist centre for treating the pancreas for every two-four million people. This is why you may have travelled a long way to come to Queen Elizabeth Hospital Birmingham. The following diagrams illustrate the different types of surgery. The first diagram shows your insides before the operation. The second diagram shows how you will look inside after the operation when the cancer has been removed.
Whipple’s operation

This is called a Whipple’s operation after the surgeon who made the procedure popular. This is major surgery. A Whipple’s operation involves removing part of your pancreas, your duodenum (the first part of your small bowel), part of your stomach your gall bladder and part of your bile duct.

As you will have part of your pancreas left behind it is unlikely that you will need to take insulin. At first, your doctor will monitor your digestion and blood sugar to make sure you can manage on your own.

Getting over this type of surgery is hard work. It will take time to get back to eating normally.
Pylorus-preserving Whipple’s or pancreatoduodenectomy

This is like a Whipple’s operation but none of the stomach is removed.

This operation is the most commonly used on the pancreas to remove pancreatic cancer. As you will have part of your pancreas left behind you should not need to take insulin. At first, your doctor will monitor your digestion and blood sugar to make sure you can manage on your own. Getting over this type of surgery is hard work. It will take time to get back to eating normally.
Total pancreatectomy
This is major surgery. It involves taking out the whole of the pancreas, your duodenum, part of your stomach, the gall bladder and part of your bile duct, the spleen and many of the surrounding lymph nodes.

Before

Afterwards

Losing your pancreas will affect your digestive system. You will also be diabetic. Losing your spleen increases your risk of infection and can affect your blood clotting.

After the surgery you will have to:

- Take enzymes to help digest food
- Have regular blood sugar checks and insulin injections
- Have vaccinations and possibly take antibiotics for the rest of your life to prevent infections (if your spleen has been removed)
Distal pancreatectomy

This means taking out the other part of the pancreas (body and tail) and leaving the head. Distal pancreatectomy is performed to try to cure cancer of the body and tail of the pancreas or to remove precancerous cysts or lesions. It is usually necessary to remove your spleen as its blood vessels run alongside the pancreas.

The head of your pancreas will be preserved, so you may not need enzymes or insulin.
Complications of major pancreatic surgery

A complication is something that happens during or after surgery that makes your recovery more difficult. Chest infections or blood clots are both common complications after any surgery.

All of these operations are major surgeries and therefore all have risks attached to them. Make sure you discuss the possible complications with your surgeon and ask all the questions you need to. It may be important to you that your family are given the chance to talk things through with the surgeons as well so please bring someone to clinic with you if you wish.

The commonest complications and the percentage of patients who develop them are:

- Bleeding 5%
- Leak or fistula 10-15%
- Infection 5-10%

You may have bleeding straight after your operation because a blood vessel tie is leaking or because your blood is not clotting properly. Bleeding in the few days following surgery can happen because there is infection or a pancreatic leak (also known as pancreatic fistula). How bleeding is treated depends on what is causing it.

A fistula is an opening. In this case, it means that part of the internal stitching to the digestive system has come apart or broken down resulting in some of the digestive juices being able to get into your abdomen. Drains put in during the operation will be left in until the fistula dries up. The fistula then usually heals on its own. Sometimes, surgery is needed to repair the leak or fistula.

Infection can develop because there is blood or tissue fluid collecting internally around the operation site or because there is internal bleeding. If you develop an internal infection, you will
be given antibiotics through your drip. Abscesses or any fluid that has collected internally will need to be drained. Draining the abscess is performed usually by putting in a drainage tube. The needle or tube is guided into place with X-ray or ultrasound.

Chest infection is a common complication of many operations. It may occur if you are not moving around enough, or breathing deeply enough after your surgery. What you would normally cough up stays in your lungs and becomes a focus for infection. You can help prevent this by doing your deep breathing exercises. The physiotherapists and nurses will get you up as soon as possible to help you get moving.

You will have had heart tests before your surgery, but as these are major operations, they will... increase the strain on your heart. Some people develop heart problems after surgery that they did not have before.

Complications after surgery can be very serious. They are becoming less common as more of these operations are done in specialist centres but even so, as many as 5-9% of people who have this major surgery die directly as a result of complications after their operation.

**When resection of the cancer is not possible**

Sometimes it is not possible to remove the cancer, even though your specialist thought resection was possible based on your scans.

This could be because the cancer has grown around the major blood vessels surrounding the pancreas, or because the cancer has spread to the liver.

These findings are not always seen by looking at scans and X-rays.

If it is not possible to resect the cancer then a bypass is usually performed to prevent future problems with bowel obstruction and/or jaundice.
Having your operation

When you are admitted to hospital for your pancreatic operation (or operation on your pancreas), you will be taking part in an enhanced recovery after surgery or ERAS programme. The aim of this programme is to get you back to full health as quickly as possible after your surgery. This booklet has been designed to give you information about your forthcoming operation.

Enhanced recovery is effective because we:

• Give you good pain relief. This will allow you to get out of bed and walk around preventing you from getting clots in your legs and muscle wasting.
• Teach you how to breathe more effectively which reduces the chances of developing a chest infection.
• Encourage you to eat and drink as soon as possible, so that you have more energy and your bowels recover from the operation.
• Encourage you to mobilise as soon as you can, by sitting out of bed and taking small walks throughout the day.

Before you come into hospital

You will be involved in planning your care and recovery from the time that we see you in clinic. This is an opportunity for you to tell us all about your individual needs and circumstances at home.

It is important that you tell us as early as possible if you have any concerns about whether you will be able to manage your daily activities when you are discharged after your operation.

You should also let us know if any of your circumstances change during your admission.

We have a team of healthcare professionals who can help to organise whatever support you might need. These include the
physiotherapy team, occupational therapists, social workers, and the discharge assessment team.

At the pre-admission/pre-screening clinic, you will be seen by an anaesthetist,...a doctor and a team of nurses to see if you are fit enough for operation. You will have a trace of your heart (ECG), blood tests and a physical examination. Some people require a chest X-ray.

You will also be given instructions about when to stop eating, what extra high-calorie drinks to have and when and what to do on the day of admission to hospital.

If necessary, the nurses in pre-admission clinic will give you information about bowel prep if you need to this before your operation.

**Day before your operation**

You will usually be admitted to hospital on the afternoon or evening before your operation. You can eat normal food until six hours before your operation. After this time you will be asked to stop eating and drinking. The ward nursing staff will provide you with some carbohydrate drinks to take at midnight and 6:00 on the day of surgery. These will help with your recovery.

**Day of your operation**

After your operation, you will be transferred to the High Dependency Unit (Critical Care Area A, Level 2). You will have several drips and tubes. They are all temporary and will be removed over the next few days. This will include a catheter into your bladder to allow you to pass urine and usually a drain into your abdomen (tummy).

Pain medication will be given either through an epidural, which gives you continuous pain relief into your back, or a pump which is attached to a drip in your arm that you will need to press. This is called patient controlled analgesia or PCA. You will also be
given tablets for pain and sickness when you are able to drink.

We would also encourage you to sit out of bed if you can as well as deep breathe to clear your lungs. Some patients can manage a short walk with help too.

The first post-op day
The nurses looking after you will encourage you to sit out of bed and gently mobilise.

The nurse will send a sample of fluid from your abdominal drain tube on the first post-op day, to measure the amount of pancreas enzyme. This is a good indication of how well the pancreatic connection (anastomosis) is healing, and will help to decide if you can start eating and drinking. The result is usually available in the evening, and if the value is low, your doctors will advise that you can start drinking fluids.

The aim is for you to take at least three walks with the help of the nurses and physiotherapists. This will be tiring and you can rest in between. This may also make you feel sore, but you will have an epidural for any pain you may have. In addition, you will be asked to take regular oral analgesia alongside your epidural.

The physiotherapists will also give you some gentle breathing exercises to do, which should be repeated each hour. You should also point your feet up and down and circle your ankles in bed to reduce the risk of clots in your legs.

The second post-op day
You will be encouraged to walk to the bathroom and sit out of bed for most of the day. You will be given regular painkillers to help you move around and get out of bed.

Your bladder catheter will be removed.

If the level of pancreas enzyme in the drain fluid is low, your nasogastric tube and abdominal drain will also be removed, and you will be allowed to start eating.
The third post-op day

Your epidural and neck line will be removed. You will be encouraged to increase your mobility, and should aim to walk without assistance. If your abdominal drain is still in, another sample of fluid will be tested.

Day four onwards

If all the tubes have been removed, you are feeling well and able to eat and drink, the doctors will start to plan you discharge from hospital over the next few days.

If the pancreas enzyme level is still high, this is an indication that the pancreas connection has not healed yet (called pancreatic fistula or leak). In this situation, your doctors may ask you not to eat anything for a period of time. Instead, you will be fed either through the nasal tube or via an intravenous line.

We will encourage you to increase your physical activity by walking around. This will help your bowels to recover and reduce the bloating of your tummy.

You will be given painkilling tablets once your epidural has been stopped. You may still feel sore because of the operation so you need to take regular painkillers. These will continue when you go home.

Complications following surgery are all reduced as a result of increasing your activity levels and should result in a shorter hospital stay.
Going home

You will be seen by the surgical team on a daily basis and they will allow you to go home if:

- You feel confident about managing at home
- You are eating and drinking as well as carrying out normal activities like getting dressed
- You do not have a temperature or signs of a wound/chest infection
- You are walking around the ward fairly comfortably
- You are passing urine without difficulty

When you are discharged you will be given a week’s supply of tablets. It is important that you continue with the painkillers until you are comfortable. This will allow you to carry out normal activities at home such as bathing, dressing, making tea etc. If you need more, you will need to see your GP. However, most patients find that the pain gets easier day by day. You will also be able to gradually increase your activity and exercise.

You will be seen routinely in the surgical clinic for follow-up care. Most patients are home within seven-ten days of this operation. Going home can be a very emotional time. You may be looking forward to it and dreading it in equal measure. These feelings are normal. You may be asked to visit your practice nurse at your GP surgery to have your wound dressings changed and your clips or stitches taken out. If your mobility is limited, you may be referred to the local District Nursing Team who will visit you in your home. Please do not feel as if you are cut off from the hospital team. If you feel you need to speak to one of the medical team on the liver unit, you can do this by phoning the ward (0121 371 7303 or 0121 371 7305) and asking them to take a message for the doctor to ring you or you may be able to speak to the doctor directly.
If we are unable to remove your cancer, you may benefit from input from your Community Specialist Cancer Nurses. Macmillan Cancer Relief usually provide these specialist nurses and they can help provide additional support or people who continue to have symptoms such as nausea, fatigue or pain, whilst at home. Your hospital Clinical Nurse Specialist will make this referral for you if appropriate when you are discharged from hospital.

It can take up to three months before you regain full fitness after your operation. You are likely to feel more tired than before the operation and have less energy. You may even begin to feel frustrated that you are not able to carry out the activities you could previously.

To help with your recovery, it is important to listen to your body. Planning a rest period during the day is helpful.

Although rest is important, mobilising is also a vital aspect of the recovery process. Gentle exercise, once your wound is healed, will help you to regain some of your previous level of independence and help avoid complications associated with surgery such as deep vein thrombosis (DVT).

Initially, you should avoid strenuous tasks such as lifting, stretching or pulling but these activities can be reintroduced and increased over the coming weeks.

When you are ready to drive will vary from person to person. Before you do drive you must be able to do an emergency stop without hesitating. We would suggest that you practice somewhere quiet such as an empty car park. Some of the pain killer medications may make you feel drowsy, if they do we would recommend you do not drive until you no longer need to take them. It is always a good idea to check with your insurance company before you do begin to drive as they may have their own restrictions.
Pancreas enzyme deficiency

Patients with pancreatic cancer often have difficulty digesting food due to lack of pancreas enzymes in the gut. The symptoms of pancreas enzyme insufficiency (PEI) may include bloating, wind pain and pale, greasy bowel motions that are difficult to flush away. This may cause you to lose weight before or after your operation. If you have any of these symptoms you will be advised to take pancreatic enzymes capsules (Creon) just before you eat. As you start to eat your meal. There is a separate leaflet detailing the medication available in clinic. The dose needed varies between individuals, and is also affected by the amount and type of food you are eating.

High fat foods such as chips, sausages, pies, pastries, cakes and any fried food will need more enzymes to help digest them. The best way to decide if you are taking enough capsules is to monitor your bowel motions. If any of the symptoms mentioned above persist, then you should increase the number of Creon capsules you take with each meal.

It is important to find the right balance of pancreatic enzymes that work for you to ensure you are digesting your food. Your dietician, doctor or specialist nurse can give you further help.

Coming back to clinic

You will be given an appointment to come back to see the surgeons when you leave the ward. Sometimes this is posted to your home address. If you have not received an appointment within a week of going home, please ring the ward on 0121 371 7303.

You will have an opportunity to ask questions when you come to clinic. It may be a good idea to write these down beforehand (there are note pages at the end of this booklet).

If you had a bypass instead of a Whipple’s (pancreatic resection) then you may see an oncologist (cancer doctor) as well as a surgeon when you come back to clinic.
The results of any histology will be discussed with you. Histology is when the tissue removed during the operation is looked at under a microscope. The results will usually confirm that the tumour removed was cancer.

The clinics that see patients after their surgery are often very busy and you may have to wait for a short time. Please bear with us if you have to wait in the Outpatients department.

Further advice

If you wish to have further information about your cancer or anything related to your illness, the following contact details may be helpful:

Ward 726
Telephone number: 0121 3717303
Liver and Pancreas Clinical Nurse Specialist Team
Telephone number: 0121 3714652

The Patrick Room

This is an information service based in the cancer centre at the Queen Elizabeth Hospital Birmingham. The people here will be able to give you the contact details of an information service closer to where you live.
Telephone: 0121 371 3539

Useful websites

- www.cancerhelp.org.uk
- www.macmillan.org.uk
- www.pancreaticcancer.org.uk
Research into liver disease and liver cancer

The Birmingham Liver Unit is one of Europe’s leading centres for research into liver disease. A team of clinical and laboratory scientists are working to better understand liver cirrhosis and liver cancer. In addition to this, we have the expertise and facilities to develop and test new treatments.

We are ideally suited to do this work in Birmingham because we have one of the largest liver transplant programmes in Europe, a large liver and pancreas surgery programme as well as a team of laboratory scientists with internationally renowned expertise in liver disease, hepatitis viruses and cancer. Our laboratories are supported by grants from various bodies including the Medical Research Council, Welcome Trust, Cancer Research UK, the British Liver Trust and from kind donations to the Birmingham Liver Unit’s Liver Foundation Trust.

For more information about our research please visit:

• www.birmingham.ac.uk/liver
• www.uhb.nhs.uk/liver-surgery-research.htm

After your operation, the diseased tissue that has been removed is taken to the laboratories and looked at to confirm the disease that you were diagnosed with. Sometimes small sections that are surplus to diagnosis requirements are taken for research.

The doctors will ask for your permission to do this. Research may involve taking cells from your tissue sample and growing them for short periods to allow experiments on them in the laboratory. Some of the cells or tissue may be frozen and stored for use in future experiments. When the research is completed the samples will be disposed of in an appropriate manner.

Please write down any questions you may have and bring this with you to your next appointment.
The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk/health-talks.htm or call 0121 371 4957.

Liver Services
Queen Elizabeth Hospital Birmingham
Mindelsohn Way, Edgbaston
Birmingham B15 2GW
Ward 726: 0121 371 7303
CNS team: 0121 371 4652